

Expanded HIV Testing

Critical Gateway to HIV Treatment
and Prevention Requires Major
Resources, Effective Protections

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Expanded HIV Testing

Critical Gateway to HIV Treatment and Prevention Requires Major Resources, Effective Protections

Phillip Nieburg, Thomas Cannell, and J. Stephen Morrison

Introduction

The early identification of HIV infection, through testing and counseling on a large scale, is increasingly understood as the critical gateway to providing individuals living with HIV with antiretroviral treatment (ART) and effective prevention and care. In the past few years, a consensus has formed among public health experts that nearly all HIV-infected people and their families could benefit significantly from becoming aware of their HIV infection. This convergence of opinion, driven principally by the recent, sudden expansion of access to ART, has been further reinforced by the new availability of reliable rapid tests and growing evidence that knowledge of one's HIV status can indeed alter high-risk behavior and reduce subsequent HIV transmission.

Expanding the uptake of HIV testing and counseling has become an urgent policy imperative for HIV/AIDS-control activities in many developing countries that are either already acutely affected by HIV/AIDS or under serious threat. As resources and programs devoted to HIV treatment, care, and prevention have increased, and as pressures have intensified to provide additional pathways for larger numbers of individuals to learn their HIV status, models for expanded HIV testing and counseling have become a more conspicuously important—and potentially controversial—subject of debate. It has also become clear that competent and responsible expansion of HIV testing and counseling requires meeting several critical challenges.

As a starting point, political and health leaders need to acknowledge, openly and forcefully, the essential linkage between expanded testing and counseling and

the ability to provide ART and prevention on a large scale. They need also to lead on a sustained basis in clarifying policies, consulting widely, and winning popular legitimacy for expanded testing. Perhaps most important, leaders have to mediate two important concerns: encouraging increased awareness by individuals of their HIV status in order to provide expanded access to ART, where available, and other care and counseling, while also ensuring the protection of tested individuals from stigma, discrimination, and abuse.

National leaders and their international partners need also to meet the true operational costs of expanded testing and counseling and to incorporate this factor into strategies and budgets for battling HIV/AIDS. The health infrastructure in most African and many other countries acutely affected by HIV/AIDS is weak, and that has first to be strengthened if effective testing and counseling is to be provided on a large scale for those who stand to benefit from access to treatment. This cannot be done on the cheap, and the true costs have yet to be systematically assessed. Either the resource pool available for treatment, care, and prevention has to be expanded, to take accurate account of the costs of expanded testing and counseling, or reallocations will need to be made that in the short term may force downward adjustments in targets for providing treatment on a large scale.

Last are two related challenges pressing upon governments and international donors alike: to expand operational research on the sociological impacts of expanded testing and treatment on stigma and discrimination, especially for vulnerable women and girls; and to devise long-term programs to redress the structural barriers to protection (e.g., empowerment of women's groups and civic bodies representing persons living with HIV/AIDS, legal and policy reforms, and other innovations to protect vulnerable groups from abuse).

Background

The staggering individual, family, and societal consequences of the global HIV/AIDS pandemic are increasingly obvious. Yet while the pandemic's impact is increasingly felt, no more than 10 percent of HIV-infected people in developing countries are aware of their infection.¹ Even as ART treatment becomes increasingly available, initial uptake has been slow—in large part because many individuals who might qualify for treatment simply do not know their HIV status. This lack of awareness and uptake is costly, given that as a general rule up to 20 percent of HIV-infected persons could benefit immediately from ART, including many who have not yet developed clinical AIDS symptoms.

The recent striking increase in new financial commitments to battle HIV/AIDS—by governments in acutely affected countries, donor governments, UN organizations, the new Global Fund to Fight AIDS, TB, and Malaria, and others—provides an unparalleled opportunity to bring HIV care, treatment, and prevention to many people in developing countries.

¹ UNAIDS/WHO, "UNAIDS/WHO Policy Statement on HIV Testing," June 2004, <http://www.who.int/hiv/pub/vct/statement/en/>.

Without knowing who is infected, however, programs are unable to provide individuals or families with appropriate care, treatment, counseling, and support. Access to ART is unlikely to be successfully scaled up without a parallel, or prior, expansion of HIV testing; the identification of each HIV-infected person generally requires that a vastly larger number of persons be tested. Consequently, rapid expansion of effective HIV testing and counseling capacity is now becoming a pressing operational and policy priority in many programs and countries.

Growing awareness of the needs and benefits of identifying HIV-infected people has generated new thinking about the process of HIV testing. In 2002, the U.S. Institute of Medicine recommended a new approach to counseling and testing pregnant women in the United States, in which HIV testing would become a routine and expected part of obstetric care, much as rubella antibody testing has become. In 2003, because efforts to further reduce overall HIV transmission in the United States had apparently stalled, the U.S. Centers for Disease Control and Prevention (CDC) began a new program (“Advancing HIV Prevention”) that included routinely encouraging HIV testing in health care settings as a part of medical care.² Recently published evaluations of such new industrialized-country approaches have been encouraging.

More recently, major international agencies such as the World Health Organization (WHO) and the UN Joint Program on HIV/AIDS (UNAIDS) have begun encouraging a shift toward an expanded model of HIV testing based on a routine offer of testing in health facilities “in settings where antiretroviral treatment is available....” Patients retain the option to not be tested (i.e., to “opt out” of HIV testing).³ These two agencies are spearheading a global dialogue on the operational requisites to ensure the success of the expanded model. Both the Global HIV Prevention Working Group, in its third report,⁴ and the Global Business Coalition on AIDS⁵ have begun advocating expanded HIV testing. The Center for Strategic and International Studies (CSIS) held a policy forum in June 2004 that focused on the challenges of framing and implementing an expanded

² R.S. Janssen et al., “Advancing HIV Prevention: New Strategies for a Changing Epidemic—United States, 2003,” *Morbidity and Mortality Weekly Report*, vol. 52, no. 15 (April 18, 2003): 329–332, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5215a1.htm>.

³ Some of the recent confusion between “routine” and “mandatory” testing practices may relate to the mandating that health workers *offer* HIV tests to their patients (on a consensual basis) versus mandating the testing itself. For example, the June 2004 UNAIDS/WHO HIV testing guidelines recommend that a “routine *offer* of testing by health care providers *should be made* [emphasis ours] to all patients...seen...in settings where HIV is prevalent and antiretroviral treatment is available.” See UNAIDS/WHO, “UNAIDS/WHO Policy Statement on HIV Testing.”

⁴ Global HIV Prevention Working Group, *HIV Prevention in the Era of Expanded Treatment Access* (Menlo Park, Calif.: Kaiser Family Foundation, June 2004), <http://www.kff.org/hiv/aids/hiv061004pkg.cfm>. The Global HIV Prevention Working Group is a panel of experts in HIV prevention convened by the Henry J. Kaiser Family and the Bill and Melinda Gates Foundations.

⁵ The Global Business Coalition on AIDS is a corporate membership HIV/AIDS advocacy organization that counts groups such as Daimler-Chrysler, Tata Steel, and Coca Cola among its 120-plus corporate members.

testing program.⁶ In 2004, under the direction of the U.S. Office of the Global AIDS Coordinator, an interagency working group was formed to refine U.S. programmatic support to expanded testing, as the President's Emergency Plan for AIDS Relief (PEPFAR) was entering its launch phase. In November 2004, WHO, UNAIDS, and the U.S. government cosponsored a meeting on priorities in HIV testing and counseling; held in South Africa, it was attended by representatives from 18 countries, including both country teams and partners.⁷ Finally, after extensive public discussion, the government of Botswana introduced an expanded HIV testing and counseling model in early 2004, and similar initiatives are under active discussion in Zambia, Lesotho, Malawi, and elsewhere.

These swiftly unfolding and historic developments have highlighted several emergent challenges.

First, the pressure to scale up treatment has also exposed the complex public health dilemma of how to raise awareness of HIV-infection status while still ensuring the individual's right to protection from stigma, discrimination, and abuse. Although access to ART is indeed slowly but steadily expanding in some places, the downside risks, including the threat of violence against people thought to be HIV infected, persist. In many countries, the most grievous HIV-related vulnerabilities and costs continue to be borne by girls and women.⁸ Thus, the increasing focus on the right of access to ART has stimulated efforts to expand HIV testing while simultaneously raising the uncomfortable question of how these twin goals—of increasing ART access and of protecting from discrimination and abuse—can be responsibly managed together. The expansion of testing may aggravate stigma, discrimination, and risk of violence, particularly for vulnerable girls and women. Alternatively, if expanded testing and expanded treatment are able to dilute stigma (as Botswana's experience may show), and if girls and women, among others, can now come forward in greater numbers to receive services, how can those changes be sustained and consolidated? Equally important, how can those gains and lessons be transferred into other, less hospitable, settings?

Second, there are several rights-based issues that require new thinking and programmatic innovations. Concerns have mounted—and may well persist for some time—that models of expanded testing could in practice amount to mandatory testing if expedience, inadequate training, and coercive approaches (whether inadvertent or deliberate) to obtaining consent in practice undermine the voluntary nature of the opt-out approach. Another concern is the need to protect individuals who choose to opt out from losing access to any services. Further, there is an active debate over whether expanded testing and the onset of costly

⁶ "Routine HIV Testing and Global HIV/AIDS Control Efforts," a CSIS conference, hosted by the Kaiser Family Foundation, Washington, D.C., June 17, 2004.

⁷ "UNAIDS/WHO/U.S. Government Consultative Meeting on HIV Testing and Counselling in the Africa Region," Johannesburg, South Africa, November 15–17, 2004.

⁸ See Janet Fleischman, *Breaking the Cycle: Ensuring Equitable Access to HIV Treatment for Women and Girls* (Washington, D.C.: CSIS, February 2004), http://www.csis.org/africa/0402_breakingcycle.pdf.

national ART programs could result in a reduction in the quality or availability of counseling and support, eroding the standards of protection that have been laid down in voluntary counseling and testing (VCT) approaches to date.

A third challenge is the need to address emerging operational questions such as whether rapid HIV tests and/or oral fluid-based HIV tests can help in the expansion of testing; whether earlier identification of persons with HIV will lower population-level morbidity and mortality; and whether an expanded approach to testing can help reduce a population's HIV-transmission rates.

Finally, and arguably most important, a formidable challenge of expanded testing is the need to bolster the capacities of already beleaguered health care infrastructures in the most acutely affected countries in a way that will make the routine offer of testing and counseling a realistic option. In many cases, simply avoiding disruptive shortages of test kits will be difficult, much less ensuring adequate pre- and post-test counseling and referral services. In some if not most cases, identifying an HIV infection and an individual's eligibility for treatment will not guarantee that treatment will become available. Despite the laudable drive by donors and governments to expand treatment access, truly affordable and accessible treatment will remain out of reach for the majority of HIV-infected individuals for the foreseeable future. Expanded testing will therefore raise difficult issues as to who among eligible persons will get priority access to ART and what kind of alternatives will be available to those for whom ART is out of reach.

In sum, if testing and counseling are to be expanded effectively, it will require major new investments by national governments and donors alike to meet operational costs that heretofore have not been adequately assessed and integrated into strategic plans and budgets. Either new resources have to be added, or adjustments will be needed, at least in the short term, to ensure the necessary investments in testing and counseling, which may entail an offsetting reduction in treatment.

A Definition of Expanded HIV Testing

For the purposes of this paper, we define expanded HIV testing and counseling as any testing scheme:

1. that includes traditional client-initiated counseling and testing at VCT centers or elsewhere; *and*
2. that also has a component in which the initiative for HIV testing comes from health workers who actively and routinely offer HIV testing and counseling as an aspect of their contact with patients; *and*
3. where those individuals offered HIV testing retain the ability to refuse the HIV-testing process.

Until now, the approach labeled as voluntary counseling and testing has been the dominant, recommended model for HIV counseling and testing among

individuals without symptoms of AIDS. VCT has generally been offered in free-standing facilities that are limited in number, often have few roles beyond VCT, and are typically only loosely linked to other components of local health care systems. The traditional VCT approach, which remains the linchpin of HIV-testing approaches, rests on: (a) governments and other care providers making HIV counseling and testing services available; (b) public awareness of that availability; (c) an individual's decision to seek out a facility providing VCT services; and (d) the individual's subsequent conscious choice to return to receive test results along with associated post-test counseling and referral. Significantly, in a traditional VCT approach, it is the individual, not the health system, that initiates action; she or he receives counseling and testing services only after having made an active decision to seek out a VCT center and be tested. This approach evolved in the 1990s, when access to ART was more limited and when stigma and discrimination were often virulent. In that early context, identification of an HIV infection typically did not trigger access to HIV care and treatment, and it was imperative for protection purposes to give special emphasis to guarding individual rights, through careful attention to the "three Cs" of pre- and post-test counseling, informed consent, and confidentiality. In many instances, VCT programs fell short of attracting large numbers of individuals to come forward voluntarily for HIV testing.

The model for significantly expanding HIV testing that is now receiving increasing attention differs from the traditional VCT approach in that, while the decision to be tested remains voluntary, it is the health system itself, and not the individual, that initiates the action resulting in the decision to be tested. When an individual patient approaches the health care system for any of various health services, many of which may be unrelated to HIV/AIDS, the health service provider routinely discusses the option of having an HIV test and routinely offers the opportunity to either proceed with the test or to opt out of being tested.

To succeed in this expanded approach, and given the challenges identified above, governments and policymakers must provide clearly articulated guidelines, sufficient new resources for staffing, training, and logistics, and leadership strong enough to ensure the legitimacy of this approach in the eyes of the public, civic groups, and health care workers. A successful expansion of testing beyond the traditional VCT model will require extensive consultations and clear and consistent explanations of the goals and mechanisms of this new approach. The opt-out approach will need to be clearly described to the public and to health care workers. Convincing assurances must be provided that counseling, consent, and confidentiality will be respected and that measures to address HIV/AIDS-related stigma and discrimination, especially against girls and women, will be strengthened. Closer and more informative monitoring of stigma and discrimination will be essential to gauge the evolving social environment in which expanded testing and treatment are put in place.

If HIV testing and counseling policies are not clearly articulated, the risk increases that there will be insufficient care to ensure truly informed consent. In particular, persons wishing to opt out must be reassured that such a decision will

not result in the loss of services beyond HIV care. But even where policy guidelines are clear, the routine offer of tests may still be mischaracterized—and mislabeled—as mandatory testing, generating additional confusion and fear.

Other Modes of HIV Testing

In addition to VCT, there are several other distinctive approaches to HIV testing:

- *Routine Voluntary HIV Testing in Antenatal Care.* One special case of VCT that already incorporates some aspects of routine testing is the targeted HIV testing of pregnant women in settings where programs are in place for using antiretroviral drugs to prevent mother-to-child transmission of HIV. Such interventions can theoretically prevent many pediatric HIV infections in developing countries, but their programmatic success obviously requires timely awareness of infection among a large proportion of HIV-infected pregnant women.
- *Diagnostic HIV Testing.* Patients seen at health facilities are sometimes tested for HIV when their symptoms create a concern in the minds of health workers that HIV infection may be involved in the cause of illness. HIV testing then becomes a routine and expected part of the diagnostic evaluation. Many of these patients are critically ill to the point of requiring in-patient care when their HIV infection is first identified.
- *Mandatory HIV Screening.* Mandatory HIV testing is generally not considered to be a component of a public health approach to control of HIV/AIDS, although it is sometimes advocated or required by the state for public safety or security concerns (e.g., when an individual's HIV status may create serious and imminent risk for others, such as blood or organ donors, or may threaten the integrity of military forces or other security services). WHO recommends that any mandatory screening program still include post-test counseling.

Botswana's Embrace of Routine HIV Testing and Counseling

Botswana has the highest GNP per capita in sub-Saharan Africa, an impressive record of democratic governance, and a relatively stable health infrastructure. Overall, 75 percent of Botswana's citizens and 95 percent of women receiving antenatal care have regular access to health care, far more than in many other developing countries. Despite these positive factors, this small African nation, with a population of 1.7 million people and with no medical school, has one of the highest HIV-prevalence rates in the world, at over 35 percent, with at least 350,000 people estimated to be HIV infected, most in the 15- to 49-year-old age range.⁹ Life expectancy at birth has fallen precipitously from 65 years in 1990–1995 to 39 years in 2004. Overall mortality rates are projected to rise from 5.7

⁹ Preliminary data from Gaborone, Botswana, suggest that the national HIV prevalence may be lower than previously thought. These data have yet to be completely analyzed and yet to be reconciled with earlier data.

deaths per 1,000 people per year in 1995–2000 to 31.3 deaths per 1,000 people by 2010–2015.

Faced with these increasingly dire projected costs to the nation—a threat to its very survival, in the words of President Festus Mogae—the government of Botswana has responded assertively. By 2003, the government was dedicating U.S.\$60 million of its own resources annually toward control of HIV/AIDS, and its HIV/AIDS budget for 2004–2005 is U.S.\$198 million.¹⁰ The African Comprehensive HIV/AIDS Partnership (ACHAP), an alliance among the Botswana government, the Merck Corporation, and the Bill and Melinda Gates Foundation, was created in 2000 with pledges of \$100 million in support over an initial five-year period (now extended), in part to support the government in providing ART to the estimated 20 percent of the country's HIV-infected citizens meeting clinical treatment guidelines. It has been estimated that those who could benefit from ART may represent more than 4 percent of the total population of Botswana.

Progress in ART in Botswana was initially fitful. An early hurdle facing the government was an inability to identify rapidly which 4 percent of citizens needed ART, due at least in part to issues such as stigma, fear of finding out one's infection status, inadequate training of health staff, and limited testing facilities. Although an estimated 20,000 of those in need of ART had already progressed to AIDS, and in those cases the illness itself indicated their need, a large proportion of those that the government and ACHAP were seeking to treat were still at an earlier stage of HIV disease—where immune function, as indicated by CD4 lymphocyte count, had decreased significantly, but where an AIDS-defining opportunistic infection (such as tuberculosis) had not yet occurred. This particular group of asymptomatic but immuno-suppressed people has the most to gain from early treatment. Yet individuals at this stage of HIV are indistinguishable from uninfected people in appearance and even on cursory medical examination. Thus, HIV testing (as well as CD4 or other testing to assess immune system functioning) is essential to identify them. For this reason, the government of Botswana and its ACHAP partners identified and announced as priority goals the strengthening of the health system's capacity to test for HIV and to actively encourage citizens to be tested. Creation of a VCT network, with direct support from the U.S. CDC and others, began in 2000 and was the initial centerpiece of that effort.¹¹ To give an idea of the magnitude of the challenge, when the government of Botswana began widespread HIV testing and distribution of ART in 2002, fewer than 20 percent of Botswana had been tested for HIV,¹² a greater proportion than in many other acutely affected countries but still a formidable obstacle to expanding treatment.

¹⁰ Phillimon Molaodi, "Parliament Approves Supplementary Estimates," *Mmegi/The Reporter* (Gaborone, Botswana), December 14, 2004, <http://allafrica.com/stories/200412140651.html>.

¹¹ As of July 2004, 16 freestanding VCT centers had been established in sites across Botswana, positioned to provide access to as many people as possible. The only function of these centers is HIV/AIDS counseling and testing for people who choose to learn their HIV status.

¹² National AIDS Coordinating Agency (NACA), *Botswana AIDS Information Survey, 2000* (Gaborone, Botswana: NACA, 2000).

The increasing availability of these VCT centers in 2002 and early 2003 was not by itself sufficient to raise the numbers of persons seeking testing and ART to desired levels however. By early 2003, after three years of VCT operation, no more than 28 percent of citizens in Botswana's most populous districts had been tested for HIV, and the approximately 10,000 people then receiving ART was far below the target that the government and its partners hoped to reach. (Many of those 10,000 people under treatment had been identified only because their progressive and severe AIDS illness had compelled them to seek care from the health system.)

A testing strategy focused on VCT alone was eventually deemed insufficient by Botswana's senior leadership. In late 2003, after extensive public discussion, including a public consultative meeting in the capital of Gaborone, the government announced its intention to expand the national HIV-testing policy¹³ to incorporate what is now in Botswana called "routine HIV testing and counseling." This new routine testing approach theoretically means that citizens of Botswana can expect to be offered an HIV test whenever they have contact with their health care system for almost any purpose. Individuals will still have an opportunity in the oral informed consent process to opt out of testing. Under this new system, the default position changed so that the responsibility falls on the patient to opt out of HIV testing if it is not wanted, rather than opting in to testing by making an active effort to seek out a VCT center and return later for test results.

The policy of routine testing officially began in Botswana in January 2004. The brief period in which the policy has been in place has not been sufficient for a full assessment of possible adverse impacts on other health services or the social consequences for individuals found to be HIV infected. The risk that the new policy might deter some people from seeking care for health problems unrelated to HIV/AIDS will eventually need to be examined in detail. However, despite the lack of comprehensive national data on numbers being tested and the absence of quality control data as of this writing, no adverse consequences of this program have been publicly reported, and some benefits are already becoming evident. Anecdotal data suggest large increases in the number of people tested. Indeed, more than 28,000 persons are now receiving ART through publicly funded programs in Botswana, and that number continues to increase. HIV testing is now expected, although not required, in many health facilities. The percentage of women undergoing HIV testing at antenatal clinics has risen from around 75 percent to more than 90 percent of attendees in the several clinics in Botswana's second-largest city of Francistown that have been closely studied.¹⁴ Women tested "routinely" were just as likely to return for their test results as were women who have been tested in antenatal clinics during the opt-in testing era.

¹³ Several of the government of Botswana's international development partners, such as UNAIDS, ACHAP, and CDC, were also involved in the formulation of policy.

¹⁴ Khumo Seipone et al., "Introduction of Routine HIV Testing in Prenatal Care," *Morbidity and Mortality Weekly Report*, vol. 53, no. 46 (November 26, 2004): 1083–1086, <http://www.cdc.gov/mmwr/PDF/wk/mm5346.pdf>.

Testing has also increased dramatically at Botswana's VCT centers since routine HIV testing in other facilities was announced. This suggests that one of the most important contributions of a routine testing policy may be that the publicity surrounding the public deliberation and the implementation of the policy can raise awareness of the importance of HIV testing as well as reduce the stigma associated with the testing process itself. In Botswana's case, the expanded testing policy is part of an explicit national campaign to reduce the stigma surrounding HIV/AIDS by focusing on it as a transmissible, treatable, and preventable infectious disease. A key component of the national program has been a well-planned, community-based communications program that uses posters, radio messages, and other social marketing techniques to encourage people to be tested. In addition, not only has President Mogae had his blood drawn for an HIV test, but he publicly admitted that a concern that he could be infected figured in his decision to be tested. Finally, it seems clear that the availability of ART has provided an impetus to the expanded testing program.

Despite these early signs of success, it is also becoming clear that implementation of the new policy has not been problem free, and there are important lessons to be learned from Botswana's experience. For example, as might be expected with any major policy shift, confusion existed for some time about the circumstances in which health workers are expected to offer testing. One interpretation of the new testing policy was that it applied to all persons 16 years of age and over; an alternative interpretation has the testing policy applying only to persons getting a "check up" and physical examination. Also, persons seeking care that appeared unrelated to HIV sometimes have not been offered testing because their medical condition on arrival at the clinic required an urgent response that precluded HIV testing and counseling.

The new testing program has also added to the resource burden on Botswana's health facilities and to the workload of already burdened nurses and other health workers. For example, delays in completion of training and heavy nursing workloads may be limiting effective HIV-prevention counseling in the expanded testing program.

The initial sharp expansion of HIV testing identified laboratory logistics and infrastructure as additional bottlenecks in the HIV/AIDS-control program. There have been shortages of materials needed for CD4 testing of the immune systems of newly identified HIV-infected individuals, and rapid test kits have also reportedly been in short supply. Even when rapid test kits are available, specimens are sometimes sent for analysis to laboratories in Gaborone, a process that may require several weeks for processing and returning results, and that negates the primary purpose of acquiring and using rapid tests. (The government of Botswana has recently stated its intent to train HIV counselors in all health facilities to perform on-site rapid tests.)

Finally, the advent of routine offers of HIV testing in Botswana and elsewhere has triggered concern in some quarters that individuals' rights may be at risk.¹⁵ Critics have argued that disclosure of HIV status to others is a complex process, the consequences of which could be severe in an environment where HIV-infected people, especially girls and women, are highly stigmatized. The reasoning is that individuals should maintain control over the time and place of HIV testing and subsequent disclosure to others. Disclosure, when it occurs, should be facilitated by counseling and other necessary social supports. The expectation that patients who come to health facilities for reasons seemingly unconnected to HIV should agree to HIV testing seemed to some observers to contravene these principles of control.

Operational Implications of Expanded HIV Testing and Counseling

In Botswana and elsewhere, a new, more assertive HIV testing and counseling policy has clarified the importance of several sets of key operational issues.

- Will persistent social risks to girls, women, and other vulnerable individuals be effectively managed as expanded HIV testing is set in place? Will counseling and post-test support systems be adequate in terms of disclosure, negotiation, and protection from stigma, discrimination, and arbitrary legal sanctions?

Expanded access to HIV testing and counseling inevitably runs up against the gender dimensions of the pandemic. In many heavily affected countries, the subordinate status of girls and women is fueling the spread of HIV/AIDS. Girls and women are often blamed for bringing the virus into the household and may risk violence or discrimination of various kinds upon disclosing their HIV status. A recent Horizons/Population Council study found that "a serious barrier to disclosure for women is fear of a violent reaction by male partners and that HIV-infected women are at increased risk for partner violence."¹⁶ In such cases, expanded HIV testing and counseling, while benefiting some women in terms of greater access to ART, could put others at greater risk, leading some to avoid seeking health care until they are at an advanced stage of illness. This problem can be particularly acute for pregnant women, who may well be the first in a family identified as HIV infected, given the amount of HIV testing conducted at antenatal clinics. Pregnant women may thus face fewer barriers to knowing their status and to receiving ART (for themselves and their fetus), but they may also face the dangers inherent in being the first identified as infected.

¹⁵ See, for example, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), *Routine vs. Compulsory [HIV] Tests 2003* (Gaborone, Botswana: BONELA, 2003), <http://www.bonela.botsnet.co.bw/Reports/SeminarReport.htm>; and Joanne Csete et al., "'Opt out' Testing for HIV in Africa: A Caution," *Lancet*, vol. 363, no. 9407 (February 7, 2004): 493–494.

¹⁶ Suzanne Maman et al., *HIV and Partner Violence: Implications for HIV Voluntary Counseling and Testing Programs in Dar es Salaam, Tanzania* (New York: Population Council, February 2001), p.1., <http://www.popcouncil.org/pdfs/horizons/vctviolence.pdf>.

Addressing complex issues such as disclosure of HIV status, stigma, discrimination, and violence ultimately requires a combination of, among other things, high-level government leadership, access to intensive counseling, and a supportive legal system. Expanded testing will need to be accompanied by extensive outreach to civil society organizations, women's groups, and networks of women living with HIV/AIDS to help ensure that protection mechanisms and referral services are available and truly accessible.

The rapid increase in the uptake of routine testing in Botswana suggests that ensuring the adequacy of post-test counseling and other interventions to support large groups of newly identified HIV-infected people does indeed require significant additional resources. Operational research will be needed to examine concerns reported elsewhere (e.g., that women identified as infected during routine [antenatal] clinic testing were less likely to inform sexual partners of their infection status than women found to be infected at VCT centers¹⁷). Preliminary Botswana data indicated equal (~85 percent) disclosure among women tested in antenatal clinics both before and after the opt-out policy began.¹⁸

At this moment, there is no single optimal approach to HIV testing and counseling. Long-term structural changes to strengthen rights and protection and to deal with stigma and discrimination will unfold incrementally. As approaches evolve, concerns about possible adverse consequences of testing and counseling will continue to require careful balancing against individuals' rights to benefit from knowing their own HIV status. For example, for most HIV-infected individuals with potential access to ART, waiting until clinical illness occurs before being tested can be problematic. Although ART is often effective in putting AIDS into temporary remission, even among persons seriously ill with AIDS, opportunities to further extend the disease-free lifespan of HIV-infected individuals can be sacrificed through delay in diagnosis. Opportunities can be missed to be screened and treated for HIV-related opportunistic diseases such as tuberculosis. So too, opportunities to carefully consider the future care of children and other family members can be reduced by delay. Finally, since nearly all HIV-infected people suffer progressive decline in immune system function and eventually develop AIDS, not being tested does not itself avoid the stigma and disclosure issues associated with HIV infection but merely postpones them until a later time when the individual has become clinically ill.

- Can an opt-out system be truly voluntary? Is "routine" HIV testing really mandatory testing in disguise?

Newspaper stories and headlines that have used the term "mandatory" to describe Botswana's new testing program¹⁹ have raised questions over whether testing is truly voluntary.

¹⁷ Ibid.

¹⁸ Seipone et al., "Introduction of Routine HIV Testing in Prenatal Care."

¹⁹ Sharon Lafraniere, "Mandatory Tests Bolster Botswana's War on AIDS," *New York Times*, June 14, 2004, p. A8. (A correction was printed on June 21, 2004.)

The term routine is defined in various places as “established,” “habitual,” “mechanical,” or “regular” (i.e., relating to a rule). The implied sense in these terms that routine HIV testing may equate to “automatic” testing may be partly responsible for the misconception that a “routine” approach to testing is equivalent to mandatory testing. In addition, the absence of the term “voluntary” in the routine testing label is not helpful. These semantic aspects argue for a terminology that more clearly indicates the noncompulsory nature of the testing and counseling process; hence the term “routine offer of testing” is increasingly—and correctly—used.²⁰

Beyond these issues of terminology, women’s subordinate status in many places can interfere with the exercise of their right to refuse testing. For example, a 2004 CSIS mission to India found that at one site, virtually all women agreed to be tested, but few stayed to receive their results. This illustrates how girls and women may feel intimidated or obliged to comply with the health care providers’ request to be tested, but at the same time perceive too many risks in actually learning their status and in acting upon that knowledge. Alternative approaches to informed consent and to counseling need to be designed to address such issues, including social and economic support issues.

- How can use of rapid HIV tests and oral fluid-based HIV testing lead to still greater success in routine testing and VCT programs?

Recent data from Botswana²¹ and elsewhere suggest that uptake of HIV testing and counseling would improve even more if test results could be returned and initial counseling provided soon after the specimen is obtained. Similarly, it is highly likely that tests that do not require blood drawing would be more acceptable to some individuals and some cultures. Because both rapid HIV testing and oral fluid-based HIV testing will raise their own policy, logistics, training, and resource questions, operational research will be needed to identify how best to incorporate them into expanded testing and counseling programs.

- Will increasing knowledge of serostatus lead to lower HIV/AIDS-related illness and mortality rates?

Earlier identification of infected people should result in large benefits to both societies and individuals in terms of preventing or delaying suffering, disrupted family life, lost economic productivity, and increased health care costs. Such benefits need to be carefully documented to sustain support for expanded testing models.

- Will use of expanded testing and counseling models result in lower HIV-transmission rates?

²⁰ The concept of expanded HIV testing and counseling has been framed in several ways. The “routine” label, as sometimes applied, has at times been interpreted to mean that if blood is drawn or if another suitable specimen is obtained for any other reason, HIV testing will *also* be suggested or encouraged. However, “routine” can also mean that if a patient comes to a health facility for *any* reason, HIV testing will be offered or suggested *even if the HIV test is the only reason for obtaining a specimen*.

²¹ Seipone et al., “Introduction of Routine HIV Testing in Prenatal Care.”

In the end, reducing the number of new HIV infections is a critically important societal goal. Expanded testing models may contribute to reaching this goal through the larger numbers of both HIV-infected and uninfected people who receive prevention counseling as part of the testing process. Operational research to examine changes in the frequency of new HIV infections should become a high priority as expanded HIV-testing programs are put in place. Such research should include monitoring of changes in rates of mother-to-child transmission.

Conclusions

Early, accumulating experience with expanded HIV testing and counseling emphasizes five central elements to an effective approach.

1. The centrality of establishing an overt policy linkage between expanded testing and delivery of treatment on a large scale, with a realistic appreciation of the implementation challenges that lie ahead.

A critical starting point is that, in the formulation of their strategies and implementation plans, national governments and donors forcefully acknowledge the critical linkage between expanded HIV testing and counseling and future success in scaling up access to ART. At the same time, they must emphasize the hard work that lies ahead in creating an effective testing and counseling system on a large scale. This cognitive step, with the exception of the cases of vanguard figures like President Mogae of Botswana, has largely been absent up until now in most national government and international donor strategies and plans.

Traditional VCT has been insufficiently resourced and supported in many places and, by itself, has proven to be a less-than-satisfactory approach to reach goals for HIV awareness in some settings. Implementation of expanded HIV testing and counseling in Botswana seems to be making an important difference in progress toward widespread awareness of HIV status. However, even in that small country, with the multiple advantages of natural resource wealth, high levels of education, literacy, and HIV awareness, and greater access to health care, progress has until recently been slow. The advent of an expanded HIV-testing model seems to have not only increased the numbers of people tested by this mechanism but also to have galvanized the traditional VCT process, perhaps through a reduction in stigma associated with the public deliberation about HIV-testing policy and with the rapid increase in numbers of people being tested through routine testing. More definitive conclusions from Botswana's experience await results of additional operational research and program evaluations. However, policymakers in other countries contemplating expanded HIV testing and counseling will struggle with implementation challenges at least as complex as those Botswana has confronted. Replication of Botswana's success elsewhere will benefit from a clear understanding of lessons being learned in this initial expanded testing and counseling experience in a developing country as well as an awareness of the local mechanics of implementing such policy change.

2. The centrality of sustained high-level leadership by national figures and international partner organizations to ensure that an expanded testing and counseling strategy is indeed carried forward.

Although indigenous leaders and international organizations may increasingly acknowledge the critical role that expanded testing can play in expanding ART, it is incumbent upon both of them to define how they will actually execute a workable strategy for expanding testing and counseling. National leaders must demonstrate resolve and sustained leadership in building popular legitimacy for an expanded national testing policy—through public outreach, clarification of policies and procedures, and a mix of policies that consciously balance promoting access to treatment with strengthened protection of vulnerable populations, especially girls and women. Confusion between the concepts of voluntary and mandatory HIV testing is likely to occur and, as in Botswana, will have to be anticipated and addressed through public education, transparent public deliberation, and adequate training of health workers.

3. The centrality of operational research to understand how expanded testing may mitigate—or aggravate—the risks of stigma and abuse.

The dynamics between increased access to ART and expanded HIV testing are not well understood today, nor is there yet a consensus on which programmatic interventions are best suited to reducing stigma and significantly increasing the number of people on ART. Local circumstances can vary significantly according to cultural, political, and institutional factors, and robust operational research in these settings is essential to understanding individual and societal responses to increased offers of both ART and HIV testing. Increased donor support for applied research in these areas will be essential.

4. The centrality of planning and adequately financing the operational costs of expanded testing and counseling.

The transition to an expanded testing model requires a much more careful and better organized planning and implementation process than has been seen thus far in most countries acutely affected by HIV/AIDS. Achievement of operational success is likely to require a strengthening of infrastructure, massive investment in additional resources, new staff training activities, development of new counseling models, and a reliable supply chain of HIV and CD4 test kits and other commodities. Here, too, expanded donor support will be essential.

5. The centrality of addressing structural obstacles.

Finally, in many places, success in expanded HIV testing will require a large investment in HIV-related structural changes—including, in some cases, changes in policies and laws—to ensure the protection of those tested, especially girls and young women. Those changes mean more programmatic support from governments and donors to civic organizations, including women's groups and networks of people living with HIV/AIDS.

Additional Readings

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